The Flaws of Communication Communicated

An Honors Thesis (HONR 499)

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Abstract

Novels that contain characters with communication disorders (medical or neurological problems with speech, language, and/or hearing) are rare. As a speech-language pathology student about to receive her degree, though, I am often confronted with how common communication disorders are in the real world. As these children grow up and reach the age where they are reading novels and thinking more critically about what they mean, it becomes even more important that they are being given stories and characters that make them feel understood. Unfortunately, there are authors that get this wrong and use disabilities and disorders to stereotype and ostracize certain characters. In this thesis, I formed a set of criteria with which to evaluate media content in order to determine whether it is appropriate for its intended audience. These criteria can be used on multiple types of media, including literature and cinema, and can apply to any and all disorders and disabilities of any age group. Following my major in speech pathology, I will be evaluating young adult novels that contain examples of individuals with communication disorders for this thesis. My goal is to give a handful of examples, both positive and negative, of novels that are evaluated for clinical accuracy, the portrayal of the individual with the disorder, and the depth and well-roundedness of character given to the individual.

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Process Analysis

This thesis is meant to inspire a discussion about communication disorders being effectively represented and accurately portrayed in literature. To focus my project on something specific, I chose to examine the genre of young adult (YA) novels from the Western world, written within the last century. I will describe the criteria I used when judging the content of these novels as well as why I picked the examples that I did. As a student studying speech pathology, it is important to me to see the population I am passionate about being actively included and represented in literature and pop culture. That being said, my target audience is young adult individuals with speech and language disorders as well as their families—although it is also important to note that this thesis could also be a useful guide to other speech pathology professionals. I not only want to see individuals with communication disorders being portrayed in a clinically accurate way in literature, but I want to see them to be shown to the audience as human beings without encouraging harmful stereotypes. It interests me to find books that I can pass on to clients or to clients' families as good examples of reading materials that include characters just like the client so that young clients can read about a character who communicates just like they do.

Before I could even start drafting this thesis, I had to pick the books that were going to be the backbone of the entire project. There was a fair amount of pressure to get this right and to find books that the audience would take interest in. One non-negotiable criterion was that each novel had to include at least one individual with a communication disorder. Since the discussion of portrayal did not require the novel to specifically portray a character in a positive light, that aspect would not discredit a book from being included. In fact, having a few different kinds of portrayals would give me a useful variety of examples to use in my thesis. From my primary

schooling, I remembered reading *Rules*—and since it was where I got the idea for the project, I knew it had to be included. *The Heart is a Lonely Hunter* was a recommendation from my project advisor. Both *the Lightning Thief* and *Harry Potter and the Sorcerer's Stone* both came from taking a moment to brainstorm deeply about popular, well-known novels that reference common speech and communication disorders. Both of these novels specifically include the key words "dyslexia" and "stutter," so as a speech pathology student, they stood out in a memorable way.

One of the other things I had to decide before sitting down to write this project was the set of criteria that I was going to use to evaluate whether or not I believed a novel was worthy of being recommended as a good example to young adult readers with similar communication disorders. I knew that the first requirement would be clinical accuracy. If a novel is going to portray a communication disorder at all, it is important that the disorder is accurate so that those who also carry that same label in real life feel as though the author did them justice by putting in the work to research their condition. The next two related criteria pertain to portrayal. To be a worthy recommendation, an author must both avoid harmful stereotyping as well as present a well-rounded, three-dimensional character.

Using these criteria as a roadmap for evaluating each novel gave me a good foundation for the rest of my paper. At times, finding appropriate sources to back up clinical information was tricky. I got stuck occasionally from being too much of a perfectionist about the way something was written instead of pushing forwards to make better progress on completing my thesis.

I found that the books I read taught me a lot about the importance of analyzing how a character is being represented. Even outside of literature, noticing what the character is being

defined by matters. If a character is clearly limited to being defined by their disorder or disability, are they contributing to the damaging stereotype that surrounds individuals with disabilities? Are they given other roles or facets to their character, or is their disability their only feature? In the past, I had not given a character's humanity much thought and just followed the drama rather mindlessly. Moving forward, I plan on sifting the media I am consuming through the criteria I formed for this project. That being said, I had a hard time when writing about Quirrell's problematic stereotypes—it felt wrong to criticize a series I grew up living and breathing. Rowling's portrayal of Quirrell was a disappointing flaw because I had so greatly admired Rowling so much as a child, but it was important to point out for the sake of realizing that any author could be capable of making mistakes with stereotypes.

Though my main sources for this thesis were the novels themselves, I also found it useful to consult data about the prevalence of communication disorders, informative academic sources about each specific disorder I researched, and other theses from likeminded scholars. One of the theses I found was of a very similar project about the inclusion of young adults with communication disorders in literature, titled "The Portrayal of Protagonists with Communication Disorders in Contemporary Award-Winning Juvenile Fiction" by Jane Lefevre. While her approach to this topic differed slightly from my own, her annotated bibliography offered many other possible novels I could have looked into had I had the time to do so. Nevertheless, I found her kindred spirit encouraging. Finding her thesis after deciding on the topic for my own gave me hope that there was an audience out there that would be interested in hearing what I have to say. I learned a lot about myself as a writer throughout this project. As interesting as it was to read the books and research papers that supported them, it made me feel even more accomplished to make myself sit down and crank out page after page. I was not sure I could

achieve this amount of volume, but after I became invested in this topic and project, the volume seemed to produce itself.

Introduction

Every good parent wants the best for their kids. They want them to grow up with good role models and for them to feel like they can do anything they put their minds to. But how many parents actually pay attention to the things their children are reading? It is easy to overlook this influence on a child's maturation because we have been raised with the idea that reading any novel is beneficial for the mind. However, what if the book has a character riddled with negative stereotypes? What if the book is inaccurate in the way that it describes someone? Especially when it comes to books with characters that have disorders or disabilities, getting the clinical facts right and appropriately giving the character his or her humanity is critically important. If the child reading the novel has the disorder or disability that the author is attempting to represent, then its accuracy matters all the more. That child deserves to read about a three-dimensional, human character free from misrepresentations and stereotypes.

This project is a review and analysis of some young adult novels from the last century that include or describe communication disorders. A communication disorder is anything having to do with expressive or receptive language that inhibits one's abilities to communicate with others and/or be communicated with. Examples of communication disorders discussed in this thesis include stutters, nonverbal individuals (who used to be called mute, though we have moved on from that terminology), dyslexia, and many others.

As they are discussed, the terminology used will be that recommended and defined by the American Speech-Language Hearing Association (ASHA). ASHA is the national board for communication disorders. All practicing speech pathologists in the United States must have their licensure through ASHA. I will also write about how the novels describe the disorder and whether these descriptions are accurate according to ASHA's standards. Finally, my conclusion

will include an analysis of the prevalence of communication disorders in the real world, whether this population is represented accurately in the literary world or not, and why that matters.

My background as a speech pathology student plays a large role in why I chose this project. It blends my two interests of literature and speech pathology. I grew up with an English teacher for a mother, so reading was something I was always encouraged to do, which I gladly accepted. I found speech pathology when I was browsing possible majors as a senior in high school. It was the perfect blend of language and health sciences, which were two of my favorite subjects. Combining these interests with my love for literature resulted in this thesis project, which I am happy to say that I feel very passionate about.

While my inspiration for this project came from a myriad of things pertaining to my major and other interests, the main spark for this theme specifically came from Cynthia Lord's novel, *Rules*. When I was brainstorming ideas for a speech-pathology related project and thought of possibly doing a literature-based thesis, I immediately thought of Lord's book, which is about a character with a severe communication disorder. Everything evolved from there, and eventually I arrived at this thesis to look at whether there are other books out there that include the same kind of population.

This project carries a bit of importance because it has to do with the representation of disordered individuals. The National Center for Health Statistics, a branch of the CDC, estimated in 2012 that nearly 8 percent of all U.S. children aged 3-17 had a communication disorder (Black). ASHA cites a near identical statistic in 2015, so we can estimate that today the percentage of individuals in that age group with communication disorders is still roughly around 8 percent ("Almost 8…"). As we become more aware of just how many people out there have communication disorders, it becomes increasingly important to make sure that these individuals

feel welcome in our society. Part of that is allowing them to grow up hearing stories with characters just like themselves so that they can be inspired by the protagonists' success and feel like they matter—even if they are different. There is something to be said about just simply feeling included as well. Even for books where a secondary character has a communication disorder, an individual with a similar condition can read that novel and feel seen.

That being said, making note of how these individuals are portrayed in their respective novels is also important. If their communication disorder is used as a means to make the character seem unintelligent, rejected from society, or unworthy in any other sense, then counting their inclusion as a valid representation would be an injustice to this project. Considering an individual to be "included" even if the novel portrays them very poorly defeats the purpose of offering individuals with communication disorders an accurate message about their personal identities.

This thesis will be a resource to individuals with communication disorders and their families, as well as to other professional speech pathologists. Having a list of places to start for finding novels that include individuals with communication disorders can be a powerful aid for those looking for novels of inclusion. Knowing which novels do their disorders justice and which ones do not is just as critical as finding the inclusive novel itself. If a novel is inclusive but portrays a character with a communication disorder inaccurately, then that is probably not the ideal choice to give to a client or loved one.

The novels I selected were ones that I knew of or ones that were recommended to me that included at least one character with a communication disorder. I did not exclude ones that I thought had stereotypes or misrepresentations of the disorder—in fact, quite the opposite. Knowing that a couple of the novels I researched had problematic portrayals of the individual

with a communication disorder helped me to better exemplify the problems I found with the representation of individuals in this population. There were a couple novels that surprised me with how problematic they were when I compared them to the thesis criteria. When presenting these novels, I ordered them from “best” to “worst” according to how well I felt that they followed these criteria as a whole.

The set list of criteria I made for this thesis came after my initial reflections on the novels I had chosen. I realized that I categorized their content into three different sections—clinical accuracy, avoiding stereotypes, and humanizing the character. It was important to me that, firstly, the disorder is written as how the actual disorder displays itself in real life. *Rules* is the perfect example of this as it showed true clinical behavior very well. Secondly, the novel was scrutinized for whether it avoided harmful stereotypes. The third criterion relates to the second, and that is whether the author creates a human character. The character must not be limited to only being an individual with a disorder, they must be given a three-dimensional personality defined by more than just their communicative abilities.

These criteria were made to evaluate whether a book could be a good recommendation for a client or their family. They can be used by another professional, a parent, or even the individual themselves if they are old enough to think critically in that manner. The goal is to inspire these individuals to think more deeply about the novels they are consuming and whether they are embracing the true humanity of those with disabilities or whether the disabilities are being used as a scapegoat to point out “flaws” in a character. Though I used these criteria within the scope of my professional field of speech pathology, they can be applied to any kind of disability or to any kind of media—not just young adult novels.

Section 1—The Books

Book 1: *Rules* by Cynthia Lord

The first novel to discuss is the one that sparked inspiration for this project. Cynthia Lord's *Rules*, published in 2006, is a story about a young preteen girl, Catherine, who struggles with making friends because she always has to watch over her younger brother, David, who has severe autism. David has a hard time with social rules and etiquette and gets overwhelmed in everyday situations. He likes to watch the same videos on repeat and often speaks in quotes from his favorite book. While accompanying her sibling to his occupational therapy meeting, she meets another boy, Jason, who is closer to her in age but cannot speak. Instead, he uses a picture board to communicate. The plot of this novel follows Catherine's emotional struggles with caring for and accepting her brother for who he is as well as the nuances of forging a friendship with someone who cannot speak to her.

Not all people with autism have communication disorders like David does, although in severe cases where the individual is on the far end of the spectrum, his communication characteristics are typical. David has a hard time finding his own words, and when he does, a lot of the proper grammar is missing. He speaks in choppy phrases and speaks telegraphically, which means he usually only retains the core words of the sentence and not the whole thing. He is also echolalic, which means that David often uses repetition of others or of audiobooks or movies instead of forming his own phrases and sentences. In *Rules*, he uses quotes from Arnold Lobel's *Frog and Toad* books, which he has on audio tape recordings that he listens to on repeat. David's echolalia is exemplified when he doesn't know how to apologize in his own words and instead quotes his favorite audiobook and scripts when Toad apologizes to Frog. Using book

quotes, television dialogue, or other references to media instead of speaking for oneself is also called scripting, which is especially common with individuals with severe autism.

David also presents a number of pragmatic issues. Pragmatics is an understanding of social "rules" and/or proper social behavior. Catherine is constantly embarrassed by David's habit of opening other people's doors and cabinets to see what is inside when they go over to Catherine's friend's house (Lord 6). Though these are both disorders of expressive language and communication, David also has trouble with receptive language. Understanding sarcasm and figurative language is a challenge for him as he takes everything very literally. David is often bullied by a boy on the bus but thinks that the bully is his friend because of the sarcastic language the bully uses when he makes fun of him (Lord 30). To try to help him, Catherine gives David a set of "rules" to help him navigate the world, which is especially helpful since David likes the structure and rigidity of rule-following. One of her guidelines for helping him understand non-literal language and behavior is "sometimes people laugh when they like you. But sometimes they laugh to hurt you" (Lord 30).

Jason's character does not exhibit as many communicative issues as David does, though his presents as more severe because of his physical disabilities. Jason is confined to a wheelchair, and though his precise medical issues are not explicitly stated, he has limited use of his hands and arms as well. He has a binder with lots of sheets full of plastic pockets containing note cards with words in them, which he locates and points to in order to communicate. A word binder or picture board like Jason uses is a type of AAC (Augmentative and Alternative Communication), which is a communication method for those who struggle to communicate verbally ("Augmentative and Alternative…"). There are many types of AAC, including unaided systems—that only require the use of the body, such as gestures and signing— and aided systems

like picture symbols and text-to-speech technologies. Aided systems are broken down further into basic and high-tech, with a basic example being a picture board (such as the one Jason uses) and a high-tech example being a computer program or tablet app that creates speech based on user input ("Augmentative and Alternative…"). To be specific, Jason uses an aided system of augmentative and alternative communication.

Part of what draws Jason and Catherine together is her ability to draw, which she uses to make new word cards for Jason's binder. Catherine often notices that Jason's selection of words is limited to his basic needs and feelings but doesn't fully allow him to use sarcastic words other kids their age typically do. Jason clearly understands sarcasm, however, because he does not hesitate to crack a dry joke when the situation calls for it (Lord 75). Catherine makes him fun word cards like "Stinks a big one!!!" (Lord 70) so he is better able to express himself like a typical kid his age, which thrills him and makes him much more excited to communicate. Catherine discovers that Jason's disability does not mean he struggles with understanding sarcasm as David does—in fact, he understands it very well, but has not had the means to use it expressively in his own system of language until he is given special new word cards from Catherine.

In the back of the print copy of *Rules*, there is a "Q&A" section with the author, Cynthia Lord and the Afterword writer Cassandra Pelham. When asked about where the inspiration for this novel came from, Lord describes her personal experience of being the mother of an autistic son. Lord also says that her daughter asked why she never saw stories of families like hers on TV or in books, which led her to give her daughter a novel featuring a story about a family with a similar structure to their own (Pelham). The details do not follow their lives to the letter, and it is not distinctly based on any true story, but the representation factor was obviously very important

to Lord, which resonated very strongly with me and my reasons for creating this thesis. Jason's character is fictional, but Lord tells Pelham that the inspiration for including him in the novel came from an instance when Lord was taking her son to therapy and saw a boy in a wheelchair using the same type of AAC as Jason to argue with his mother. It dawned on Lord that "he could only use words that someone else had given him" (Pelham), so Jason's character began to develop from there. Since Lord's inspiration for Jason came from a real encounter, her characters seem especially human and perfectly exemplify the two final criteria.

Given that Lord's novel is based on her personal experience of having an autistic son, her account—though in the form of fiction—seems to be very reliable. Though I had read this novel once in grade school, I was pleased to read it again as a speech pathology student and recognize for myself that her portrayal of David and Jason are clinically very accurate.

In a genuine clinical setting, individuals with Autism Spectrum Disorder (ASD) can present with many of the same characteristics as David. Since it is a spectrum, every individual with ASD is unique. On the more severe ends of the spectrum, it is common for individuals to be very literal, have sensitivities to certain sound, textures, or other stimuli, and to have difficulty with pragmatic behaviors and picking up on social cues.

I was really impressed by *Rules*. It passes all three criteria across the board, and it includes not only one but two main characters with communication disorders. It would be a beneficial read for any potential client, their family members, or another professional. A family member reading this novel may initially relate to Catherine's frustration with her younger brother, but seeing Catherine learn new things about individuals with communication disorders through her friendship with Jason may inspire them to pursue a similar relationship of

understanding with their own loved one. *Rules* would give a young reader a character that is just like them—a character that is still worthy of friendship, understanding, and humanity.

Book 2: *The Heart is a Lonely Hunter* by Carson McCullers

This novel from June 1940 is centered around a man named John Singer, who is both deaf and mute. The story begins with Singer and his friend, Spiros Antonapoulos, who is also deaf and mute. The two of them are living together as roommates in a small town and spend all of their time together except when they are at work. The two are clearly very close. The narrator notes that neither of them has any other friends, most likely due to their inability to communicate verbally, but they seem content with this. As the first chapter progresses, Spiros is sent away to an asylum by his cousin as his mental health and intellectual disabilities appear to worsen. John Singer is immediately depressed without his friend, though constantly paying for the trouble Antonapoulos caused in town was becoming a burden.

Singer is described as well-dressed, intelligent, and a skilled worker (McCullers 3). He knows both American and European sign language and reads lips, but he found learning to speak verbally too challenging to master (McCullers 11-13). He enjoys a modest, plain life and the narrator states “his eyes had a quick, intelligent expression” (McCullers 3). Most often he uses a pad of paper to communicate with the people in his community. The audience gravitates towards him.

His counterpart Spiros Antonapoulos, however, is portrayed much less favorably. With a physical description resembling that of someone with Down Syndrome, he is described as having “half-closed eyelids and lips that curved in a gentle, stupid smile” (McCullers 3). More unkind description paints Spiros as morbidly obese, lame, and lazy with a disheveled, hapless lack of dress sense. His endless appetite and obsession with food is his driving motivation for anything he does, and he is given menial grunt work at his cousin’s grocery shop in town (McCullers 4). While Singer is a fluent and avid signer, Spiros only knows a handful of hand signs. The

audience is given the impression that he does not pay attention to John's flurry of signs to him nor does he understand them (McCullers 3).

Clinically, there is not much to dissect. Deafness is a straightforward condition—as far as effects on speech go— that, if present at birth, eliminates most chances for the individual to ever develop verbal speech. Realistically, it would be a challenge to try to create speech and articulate it effectively without having ever heard it. Etiologies of deafness are much more complicated, but that ventures into the territory of audiology, so we will focus on the effects of deafness on verbal communication. Adaptations to this hearing loss include teaching the individual to read and write, sign, and read lips—all of which we see Singer using. The audience is left to assume Antonapoulos cannot read, write, or read lips and only signs a couple of words.

However, if we follow the theory that Spiros Antonapoulos, the "obese and dreamy Greek" (McCullers 3), has Down Syndrome, this may begin to explain his shift in behavior. Some individuals with Trisomy-21 (Down Syndrome) are at risk for developing dementia earlier than individuals without the extra chromosome. Chromosome 21 is known for carrying the amyloid precursor protein (APP) gene associated with causing plaques that lead to dementia ("Alzheimer's Disease"). An extra copy of this gene increases the presence of APP, which may explain why almost all individuals with Down Syndrome show signs of these plaques by 40 years old, which then leads to early-onset dementia in approximately 50 percent of individuals with Downs ("Alzheimer's Disease"). Since Spiros has Down Syndrome and John Singer noticed his friend's behavior worsening as he began to show signs of aging, this would make dementia more plausible as the culprit for his deteriorating behavior. As he worsens and what little abilities he possesses begin to decline, the behavioral trend of his deterioration follows that of dementia. Soon enough, he is sent away to an asylum where he can be contained.

As the oldest of the four novels on the discussion list, the way it looks at disability (both intellectual, physical, and otherwise) is much less politically correct than Americans expect today. *The Heart is a Lonely Hunter* was written in the 1940s, but it takes place in the ‘30s. As more research has been done and we have become more enlightened about treatment, diagnosis, and the overall potential individuals with disabilities have to learn and function, we can look back on novels like this and see the humanity in these individuals that the community members in the novel did not.

John Singer, after losing his dear companion, struggles to find a sense of belonging for the rest of the novel. Though he meets many other individuals in his community, he loses the one person he had a true shared experience and outlook on life with. Though some others are sympathetic and kind towards him, they would never be able to see the world the way he does, no matter how much he tries to explain on his pad of paper. This portrayal of isolation and longing for connection by the narrator suggests that the author, McCullers, has more insight into the heart of individuals with disabilities than she gives to the narrator or some of the other characters in the novel. She shows Singer looking for human connection and struggling to find community amongst three other signing individuals he meets after Spiros dies, showing that she understands his human need for acceptance and comradery (McCullers 390). Though Spiros Antonapoulos is described unfavorably by the narrator as visually unappealing and behaviorally disturbing, I believe this was deliberate to show how others in the community viewed him. The fact that this novel is so heartfelt about showing the real, human feelings of someone other humans rejected at the time leads to the conclusion that the author herself must not view these individuals as the way the general public would have viewed them.

McCullers may have portrayed Spiros in a way that makes the audience uncomfortable for a reason. Though it has some obvious issues with stereotyping, Singer's character is so dynamic that it seems impossible for her to have fallen into these stereotypes by accident. It then stands to reason that the discomfort of the audience juxtaposed with their deeper understanding of Singer is a device being used specifically to point out that beneath the stereotypes of Antonopoulos lies the same kind of humanity—an individual with feelings and wants and a need for community. This forces the audience firsthand to notice the stereotype for themselves. Perhaps McCullers meant for this to nudge the audience towards changing their outlook on the actual individuals with disabilities in their own communities. Though our first impression of these individuals may be clouded by the stereotypes forced on the subject of disorders, syndromes, and disability, there is hope that we may be reminded of the depth of Singer's character and look at these individuals with more understanding.

Though the book itself is older and less clinically specific, there were not any glaring inaccuracies. The other two portrayal-related criteria were less conclusive, however, since there were two characters with communication disorders which were each given a different tone. The portrayal of John Singer is very three-dimensional, whereas Spiros is incredibly basic. Singer is given depth and palpable emotion and a dynamic personality. We never see into Spiros's emotions or get to know any of his other characteristics other than being described as fat, lazy, and unintelligent. Some of Spiros's descriptions err on the side of negative stereotyping. Singer's description does not. It seems that the communication disabilities the two characters share—being deaf and mute— are not the driving factor for these stereotypes, but rather they stem from the physical and intellectual limitations of Antonopoulos. Physically and intellectually, John Singer appears intact, while Spiros seems much more impacted. I admit I am conflicted about

recommending this novel to young adults. The theme is much more mature as it deals with death and depression, but it could be appropriate for someone in late high school. I would not recommend this to younger readers who have not matured emotionally. At surface level, the portrayal of Spiros is problematic. Only after considering the context of the time period that the novel was written in can we see that the portrayal of this character may be a commentary about how individuals like Spiros were viewed and treated by society. Following McCullers's portrayals of the two friends, it painfully convicts the public for choosing who can and cannot be "human." While this novel is a valuable read for adults, I would not consider it a viable recommendation for individuals looking for books that help those with communication disorders feel represented.

Book 3: *The Lightning Thief* by Rick Riordan

The Lightning Thief, published in 2005, has been read by almost every American student in at least my generation. The fact that it includes a communication disorder is overlooked by almost everyone. Percy Jackson, the main character, narrator, and protagonist, was diagnosed with dyslexia. In the introductory chapter, he tells the reader that "I have dyslexia and attention deficit disorder and I had never made above a C- in my life" (Riordan 15). Dyslexia is classified as a learning disability and a written language disorder by ASHA because it is described as an interruption in "reading decoding and sight word recognition" ("Written Language Disorders").

From a clinical standpoint, this is a difficult one to assess. Dyslexia is a name used to describe reading difficulties, but how that expresses itself from person to person can vary. However, one common misconception is that dyslexia makes the letters look like they're swimming around the page. While this may be an analogy for a mental sensation caused by the confusion or frustration of not being able to read easily, dyslexia does not cause visual symptoms. Instead, the confusion is from misconnections between letters and sound associations in the language centers of the brain. Percy attributes neon signs, "fancy script" (Riordan 32), and other types of text to factors that worsen his dyslexia. Researching the factual basis for these claims proved inconclusive as there are no research publications about them, and any search for other sources were unreliable blogs or forums that yielded conflicting answers. I found no evidence that the type of script had any impact on the "readability" of text by individuals with dyslexia, which leads me to believe Riordan did not gather his symptoms of dyslexia from a verified medical source.

Though his interpretation and clinical portrayal of dyslexia seems largely inaccurate, Riordan may be doing something purposeful by getting dyslexia wrong—though I would argue

that he is still misguided. Percy recalls the school counselor telling him that it is just his "brain misinterpreting things" (Riordan 18), though he hints that he feels like there is more to it. The "human world" that Riordan continually sets Percy farther and farther from is the only source of his dyslexic diagnosis. However, what was once seen as a learning disability takes a turn once Percy's demigod identity is finally revealed. His dyslexia when reading English is supposedly because he is meant to follow his divine Greek lineage and read Greek instead. Upon his arrival at Camp Half-Blood, his companion asks him, "The letters float off the page when you read, right? That's because your mind is hardwired for ancient Greek" (Riordan 100). Sure enough, he soon finds out that ancient Greek is much easier to learn. If this "superpower" causes his ability to read any other language to be so abysmally difficult, then it makes sense that the only explanation the human world—with no knowledge of the demigod realm— would have for his symptoms would be his diagnosis of dyslexia. Riordan's misrepresentation of the disorder may have been deliberate after all, though it does seem to abuse the reality of individuals living with a communication disorder.

What does this mean for anyone reading or listening to this novel who does have dyslexia? It is possible that they will still be able to identify with Percy's difficulties with learning in a traditional school setting. However, if they were looking to him as a role model or as a story of success, they may be disappointed to discover that he does not truly "overcome" his learning disability at all. Percy is given a miraculous (and fictitious) way out of it. If one only takes the story at face value for the pure fantasy and adventure, this should not be much of an issue. The fact that Percy has "dyslexia" at all is mostly glossed over and overshadowed by the rest of the plot, anyway. But for those who are looking to be represented, this could be a real disappointment.

While clinical accuracy is an issue, Riordan can be applauded for the well-roundedness of Percy as a character. He highlights Percy's personal growth as he adjusts to his new life in the demigod realm and the absence of his mother. Percy has a number of dynamic friendships and relationships that also change and grow as the novel progresses. Though Percy does not actually have dyslexia, Riordan avoids stereotyping him. His supposed dyslexia is not the center of attention that his character revolves around, nor is he defined or limited by it. In this way, I think Riordan presents an effective character model.

Book 4*: Harry Potter and the Sorcerer's Stone* by J.K. Rowling

It would be surprising for someone reading this thesis to have never read or at least heard of this novel. *Harry Potter and the Sorcerer's Stone,* released in 1997, is an asset to modern pop culture, and yet its inclusion of communication disorders is often overlooked. The secret villain of the novel, Professor Quirinius Quirrell, exhibits a stutter. Whether readers realize it or not, his stutter plays a large role in why his character's evil deeds are never suspected.

When readers are first introduced to Professor Quirrell, he is described as nervous and "trembling" (Rowling 70). As such a shaky man, it would seem fitting that he also stutters. The verbs used to describe his speech mimic his condition— "'P-P-Potter,' stammered Professor Quirrell…" (Rowling 70). The initial consonant of most of his words are repeated a couple of times before his speech continues on. Though not every word is impacted by his stutter, the reader gets the idea. Looking through his dialogue, the majority of the consonants in the English alphabet presented with a stutter, including p, c, t, d, n, g, b, and m. Words that begin with vowels are less impacted, which is common for those with stutters.

Adults that stutter, however, are rare. "Fewer than 1% of stuttering cases are in adults" ("What Causes Stuttering?"), states an American Academy of Family Physicians editorial. This makes the true clinical accuracy of Quirrell's case a little more doubtful. Quirrell was said to have only become jittery and nervous towards everything—even his own Defense Against the Dark Arts teaching position—after having a traumatic experience in a dark forest with vampires or other dark creatures, according to Hagrid (Rowling 70). If this trauma caused the jumpiness so often characterized by his stutter, it can be assumed that this was also the onset of his fluency issue. The editorial referenced above also cites that "emotional and mental health problems" (Staff) are a possible etiology for stutters. William Perkins's research study on the treatment of

stuttering disorders agrees that there are “extreme emotional reactions to environmental pressures that result in fluency disintegration” (Perkins 23). Clinically, Quirrell’s case is uncommon, but not impossible.

As the plot of this novel progresses, however, Quirrell’s stutter turns into something far less innocent. Spoiler alert—he is the bad guy, and Voldemort lives on the back of his head. As he is confronted by protagonist Harry Potter, he drops his guise of fragility and innocence and his stutter disappears as he gives a villainous speech about his true intentions. “‘Who would suspect p-p-poor, st-stuttering P-Professor Quirrell?’” (Rowling 288), he jeers in mimicry of his own stutter. Quirrell does not stutter again for the rest of the scene. As evil showed itself at last, his fluency returned.

This portion of the novel presents a disconnect with communication disorders that has nothing to do with clinical accuracy—instead, the portrayal of the stutter as a mask shows an inaccuracy that infiltrates the description of communication disorders in literature. Oftentimes, disabilities or other “imperfections” are used to denote evil, suggest a lack of intelligence, show some kind of deeper lack of humanity, or otherwise enforce a damaging stereotype (Beauchamp 73). Quirrell’s stutter is employed to show him as weak or incapable of calculation—as if his speech disorder somehow makes him physically or mentally unable to be evil. Surprisingly, though, the audience buys in. His stutter adds to his unassuming demeanor and he becomes the most unlikely suspect, even though all of the evidence of his guilt was there.

Honestly, I was quite saddened by what I found in this novel. As a lifelong fan of Rowling and of the entire Harry Potter franchise, seeing a character with such glaring stereotypes was unfortunate. Like a disappointed parent, I wanted to chastise Rowling and tell her that I expected better out of her. The clinical portrayal of the stutter was iffy, but even worse,

Quirrell's stutter was a get-out-of-jail-free card to exempt him from actual human characteristics. Instead of allowing him to have actual deceptive behavior or manipulative speech, Rowling gave him a stutter to force the illusion that someone who is "broken" cannot be capable of being a mastermind villain. While I cannot help but continue to enjoy the rest of the series aside from the Quirrell debacle, it goes to show that no author is exempt from creating flawed, stereotyped characters.

Section 2—Representation

To say that only eight percent of all U.S. children have a communication disorder makes that fraction of the population sound negligible. The overwhelming majority—the other 92 percent of the population—are "normal," so why should there be books about characters with communication disorders? The Annie E. Casey Foundation reveals that based on the 2010 census, the United States alone has 74.2 million children ("The Changing Child…"). Eight percent of 74.2 million is more than 5 million. Five million American children have some kind of communication disorder. Five million children deserve to have accessible novels of characters just like them. Even one child deserves to be able to read about someone they can relate to.

Miles Beauchamp, author of *Disabled Literature: A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature,* references a study by Baskin and Harris as a part of his own research that states from 1976 to 1981, there were only 348 books total (fiction and nonfiction) written about any kind of disability. He mentions communication disorders, then called "speech and cosmetic problems" (Beauchamp 134) as one of the smallest-mentioned book subjects in that study. Though times have changed, Beauchamp's conclusion that "it takes a special effort to find these books" (Beauchamp 132) remains the same. Books about individuals with disabilities or disorders are under-publicized and picked less often by reviewers.

A likeminded thesis by Jane Lefevre found during my own search for literature about this topic was my greatest resource for finding books about individuals with communication disorders. Her annotated bibliography offers a handful of other novels I had never heard of before that I could not find while browsing the internet. Had I had the time to do an extended amount of research on this topic, I would like to have gotten the chance to read some of the other

sources she included in her thesis, such as *The Dreamer*, *Harmonic Feedback*, and *Out of My Mind*—all of which focus on individuals with communication disorders.

I only came up with a dozen or so possible titles on my own search for inclusive novels. Out of the hundreds upon thousands of books in school libraries, what are the odds that a single child in that 8 percent of the population with a communication disorder could find one of those books? Even if they do find a book about an individual with a communication disorder, how likely is it that the novel avoids negative stereotypes? Those children deserve to feel included, accepted, and most of all, human.

Section 3—Summary and Conclusion

Writing this thesis prepared me for a side of my professional career that none of my other courses have prepared me for thus far. As a speech pathologist, I am expected to provide therapy as well as be a source for education and helpful resources for my clients, parents, and families. I am also expected to collaborate and offer my knowledge to other professionals. While I've been prepared to be professional, courteous, and knowledgeable about my field, I was less sure about good resources to recommend to the individuals with whom I work.

Reading is an important factor in helping young minds develop linguistically, and it is common for younger, school-age clients to see speech pathologists for help with literacy. Knowing that I have a working set of criteria with which to evaluate the books I can recommend to my clients makes me feel more competent. I know I have the means to help them find a suitable novel about an individual with a communication disorder just like theirs. In addition, it feels uplifting to know that I can pass this three-criteria system on to other speech pathologists or educators in my community. Hopefully, each child in the eight percent that passes through the school system or community I work with can feel like someone is at least making an effort to help them feel included.

I was surprised by the things I found in my example novels. I was not expecting one of the most popular novels of the 21st century to have a glaring stereotype as a main character, nor was I expecting an author as skilled as Rick Riordan to be so clinically inaccurate. I honestly struggled with criticizing authors that I had grown up liking so much. But I was pleased by the way that *Rules* turned out to be the perfect example of what I was looking for in my project. Though having examples of what not to do was helpful for showing the need we have for good

examples of disorders in literature, showing a novel that got it right is an even better roadmap than the ones that got it wrong.

I hope that those reading my thesis come away from my writing even just a little more enlightened than when they began. I hope that they analyze the media they consume with a little more scrutiny when it comes to the way all individuals are portrayed and represented. Most of all, I hope the audience will take my three criteria and use them to help others within their families, communities, or scopes of practice to find novels that make them feel included.

Works Cited

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"Alzheimer's Disease in People with Down Syndrome." *National Institute on Aging*, U.S. Department of Health and Human Services, www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome.

"Augmentative and Alternative Communication (AAC)." *Augmentative and Alternative Communication (AAC)*, ASHA, www.asha.org/public/speech/disorders/AAC/.

Beauchamp, Miles. *Disabled Literature: A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature*. BrownWalker Press, 2015.

Black LI, et al. "Communication Disorders and Use of Intervention Services Among Children Aged 3–17 Years: United States, 2012." *NCHS Data Brief*, no 205. Hyattsville, MD: National Center for Health Statistics. 2015.

"The Changing Child Population of the United States." *The Annie E. Casey Foundation*, www.aecf.org/resources/the-changing-child-population-of-the-united-states/.

Lefevre, Jane. "The Portrayal of Protagonists with Communication Disorders in Contemporary Award-Winning Juvenile Fiction." (2015). *Graduate Theses, Dissertations, and Problem Reports*. 6054. https://researchrepository.wvu.edu/etd/6054

Lord, Cynthia. *Rules*. New York: Scholastic, 2009.

McCullers, Carson. *The Heart Is a Lonely Hunter*. Modern Library ed. New York: Modern Library, 1993.

Millikin, Cynthia C. "Picture Symbol Topic Boards for Written Language." *Perspectives on Augmentative and Alternative Communication*, vol. 16, no. 1, Jan. 2007, p. 13., *American Speech-Language-Hearing Association*. doi:10.1044/aac16.1.13.

Perkins, William H. *Stuttering Disorders*. New York: Thieme-Stratton, 1984.

Riordan, Rick. *The Lightning Thief*. Disney-Hyperion, 2018.

Rowling, J. K. *Harry Potter and the Sorcerer's Stone*. New York: Scholastic, 2000.

"What Causes Stuttering? - Stutter." *Familydoctor.org*, 14 Nov. 2018, familydoctor.org/condition/stuttering/.

"Written Language Disorders." *Overview*, ASHA, www.asha.org/Practice-Portal/Clinical-Topics/Written-Language-Disorders/.

Annotated Bibliography

Subtitled Sources: What My Sources Have to Say

"Almost 8 percent of U.S. children have a communication or swallowing disorder." *ASHA Leader*, Aug. 2015, p. 10. *Gale OneFile: Health and Medicine*, https://link.gale.com/apps/doc/A425914438/HRCA?u=munc80314&sid=HRCA&xid=e558cbe1. Accessed 17 Jan. 2020.

This is ASHA's (American Speech-Language-Hearing-Association) article on prevalence of communication disorders. ASHA is the national certification board for speech pathologists and has several different journals for reference of specific disorders and the latest research about prevalence and treatment. I will use this article specifically when talking about prevalence of communication disorders which leads to a discussion about representation.

"Alzheimer's Disease in People with Down Syndrome." *National Institute on Aging*, U.S. Department of Health and Human Services, www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome.

This source has facts and links to research associated with Down Syndrome and dementia. I will use this when talking about Spiros's possible condition, which is hinted at in the first chapter. His physical descriptions match those of an individual with Down Syndrome, especially the points about his droopy eyelids and insatiable appetite. I will explore the possibility of this being the cause for his worsening behavior, resulting in his cousin committing him to an asylum.

"Augmentative and Alternative Communication (AAC)." *Augmentative and Alternative Communication (AAC)*, ASHA, www.asha.org/public/speech/disorders/AAC/.

ASHA's main website has a section that gives an overview of this communication aid and gives basic definitions of types of AAC. It also briefly describes how AAC is used in practice for speech pathology, which will be useful when I talk about how AAC is referenced and used in *Rules*.

Beauchamp, Miles. *Disabled Literature: A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature*. BrownWalker Press, 2015.

This source doesn't specifically focus on communication disorders, though they are alluded to or briefly mentioned from time to time. Rather, it focuses on the overarching umbrella of disabilities that communication disorders fall under. It has been helpful for seeing how people with disabilities are affected by the way they are portrayed in literature, media, and overall public opinion. It confronts stereotypes, inclusion, and portrayal.

Black LI, Vahratian A, Hoffman HJ. "Communication Disorders and Use of Intervention Services Among Children Aged 3–17 Years: United States, 2012." *NCHS Data Brief*, no 205. Hyattsville, MD: National Center for Health Statistics. 2015.

This is an American CDC source about the prevalence of Communication disorders in children/young adults. The age group I'm interested in as the audience for YA novels is included in this. It has helpful graphs and charts as well as a breakdown of some of the types of disorders mentioned.

"The Changing Child Population of the United States." *The Annie E. Casey Foundation*, www.aecf.org/resources/the-changing-child-population-of-the-united-states/.

This article offers reliable data about the population of children in the United States as of 2010. Though a decade old, it appears to be a close match with other more current (but less reliable) sources.

Lefevre, Jane. "The Portrayal of Protagonists with Communication Disorders in Contemporary Award-Winning Juvenile Fiction." (2015). *Graduate Theses, Dissertations, and Problem Reports*. 6054. https://researchrepository.wvu.edu/etd/6054

This dissertation has been helpful at showing me other possible novels I can analyze for my thesis, such as *The Dreamer* (which is a fictional biography about Pablo Neruda, who stuttered as a child), *Harmonic Feedback* (featuring an individual with Asperger Syndrome, a type of pragmatic and social communication disorder), and *Out of My Mind* (a novel dealing with Cerebral Palsy and more AAC). Having access to these titles that I had not known of previously is incredibly useful when it comes to possibly expanding my research. It also has useful information as far as organization of the paper itself. Lefevre takes a slightly different approach than I am planning to, but we have kindred spirits in that we're exploring the same subject matter.

Lord, Cynthia. *Rules*. New York: Scholastic, 2009.

David has autism and struggles with communicating. He mainly uses echolalia, a type of imitation (both of other family members or of movie and book quotes). When he does communicate, he exhibits a lack of understanding of social pragmatics—which refers to understanding of the social "rules" of interacting with others. Jason, another boy that goes to the same therapy clinic as David, has an unknown condition that leaves him

wheelchair bound and he relies on a picture board to communicate. A picture board is a type of AAC (augmentative and adaptive communication), and though it is not a communication disorder in and of itself, it is a type of treatment or adaptation to whatever is causing him to be nonverbal. Several types of communication disorders and/or atypical communicative methods/behaviors are presented in this book, such as echolalia, pragmatic difficulties, and the use of AAC. This book was the main inspiration for my project.

McCullers, Carson. *The Heart Is a Lonely Hunter*. Modern Library ed. New York: Modern Library, 1993.

This book examines what was once called deafmutes. It refers to a deaf individual that is nonspeaking. I will be examining both the nonverbal aspect of this character due to his being deaf and the portrayal that is affected by this communication block. It was written in June of 1940, but takes place in the 30's, which might affect how the individual was portrayed since those with communication pathologies were misunderstood as being intellectually disabled at this time. Though there can be overlap between communicative and intellectual disabilities, they're not mutually exclusive.

Millikin, Cynthia C. "Picture Symbol Topic Boards for Written Language." *Perspectives on Augmentative and Alternative Communication*, vol. 16, no. 1, Jan. 2007, p. 13., *American Speech-Language-Hearing Association*. doi:10.1044/aac16.1.13.

This ASHA journal article describes how AAC is used, which will be useful when I talk about Jason's character in *Rules* and how he communicates with those around him.

Perkins, William H. *Stuttering Disorders*. New York: Thieme-Stratton, 1984.

A current source from an author who also writes publications in ASHA's most esteemed journals about stuttering disorders, providing the reference I need to talk about Professor Quirrell's disorder. This publication describes what a stuttering disorder is and even talks about some treatment options, though I will not get into that for my paper.

Riordan, Rick. *The Lightning Thief*. Disney-Hyperion, 2018.

Percy Jackson struggles with what has been diagnosed as dyslexia in a normal school setting before finding out that he is a demigod. The idea in this book is that he is meant to read Greek instead, so everything else appears as a jumble of words and letters. The communication disorder I'm attempting to look at in this novel is dyslexia.

Rowling, J. K. *Harry Potter and the Sorcerer's Stone*. New York: Scholastic, 2000.

The main villain in this book, Professor Quirinius Quirrell, exhibits a fluency disorder (a stutter). The communication disorder that I will be talking about with this source is a stutter. This also has some interesting viewpoints about portrayal as he is not the protagonist in this novel. His stutter was partly used to make him appear weak or innocent, as if his stutter made him incapable of being diabolical.

"What Causes Stuttering? - Stutter." *Familydoctor.org,* 14 Nov. 2018, familydoctor.org/condition/stuttering/.

This article from the American Academy of Family Physicians offers helpful information about what a stutter is and possible causes of this fluency issue. It also has details about sounds that individuals with stutters typically struggle with and possible ways to treat it. For my thesis, this article gives me helpful information about common stutter issues so that I can compare them to what I see in Professor Quirrell's speech.

"Written Language Disorders." *Overview*, ASHA, www.asha.org/Practice-Portal/Clinical-Topics/Written-Language-Disorders/.

This article gives an overview into what dyslexia is and what kind of difficulties it causes. I will use this article when talking about Percy Jackson's diagnosis.